



**Arizona Department of Health Services
Office for Children with Special Health Care Needs
Integrated Services Grant**



**ISG Young Adult Transition Committee
July 20, 2006
Meeting Minutes**

Attendees: Theresa Armstrong, Mattie Cummins, Jay Dashefsky, George Garcia, Jason Geroux, Debbie Gilmer, Katie Griffith, Linda Hamman, Odell Joshua, Janette Maldonado, Shannon Shiver, Samantha Tunis

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
Pre-meeting notes		<p>The ISG Young Adult Transition Meeting of 7-20-06 was a detailed working meeting. Decisions were made on the structure of the committee in regards to designating a young adult Chairperson and Co-Chairperson. Feedback was given on the GAPS Questionnaires (Guidance for Adolescent Preventive Services) for inclusion into a report to the ISG Task Force. Brainstorming on topics and next steps of the ISG Young Adult Transition conference/summit was also completed.</p> <p>Attendees via conference calling: Jay Dashefsky, Katie Griffith, and Debbie Gilmer</p>	
Welcome and Introductions	Linda Hamman, ADHS-OCSHCN	<p>Welcomed all the participants to the meeting. The group was informed that Beverly Plonski-Fuqua of the ADHS-OCSHCN office will be the facilitator for this committee.</p> <p>The members also welcomed Ms. Debbie Gilmer from the Maine Support Network, Western Maine Partnership, UMF. A bio was furnished within the meeting handouts. Ms. Gilmer comes to the ISG Young Adult Transition Committee as a colleague/consultant of Ms. Patti Hackett at the Health & Ready to Work National Center. Welcome Debbie.</p>	<p>*Beverly Plonski-Fuqua will be facilitator for the ISG Young Adult Transition Committee. Please contact her at plonskb@azdhs.gov or 602-364-3291 with any ideas, concerns, or adding of new participants.</p>
Introductions	Group	The committee members took a moment to introduce themselves.	
Review of 6-12-06 Meeting Minutes	Group	The members reviewed and accepted the meeting minutes of 6-12-06 with speaker designation corrections.	*6-12-06 Meeting Minutes were accepted with corrections.

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	Theresa Armstrong, AZDOE	Advised the group that the AZDOE website is currently under construction and some links may not work at this time but will be re-established soon.	*AZDOE website under construction but check back to see if links are re-established.
Handouts		The handouts for the 7-20-06 ISG Young Adult Transition Committee were as follows:	
		Agenda 7-20-06 Debbie Gilmer BIO – Welcome new member 6-12-06 Meeting Minutes to approve 5-8-06 Meeting - Brainstorming Notes ISG Young Adult List of Participants – new ISG Young Adult Transition Net Resource Listing-paper ISG Young Adult Transition May 2006 Status Report to Task Force ISG Young Adult Transition Action Item Report (from minutes) GAPS (Guidance for Adolescent Preventive Services) Questionnaires for review and comment ISG CD of Internet research resources-with table of contents Evaluation Forms	*Visit www.azis.gov for all current ISG Young Adult Transition and IS Grant information.
		Paper copies distributed of the following:	
		-Family Involvement Center fact sheet from website -AZDOE Exceptional Students –webpage print outs *Youth Empowerment and Self Determination webpage print out *Transition Services webpage printout *Parent Networks Training/Event Detail webpage printout -National Coalition of Self-Determination – from Center for Self Determination -Transition Timelines -3 sheets -Fact Sheet on Health Insurance Options in Washington State for Young Adults with Disabilities and Special Health Care Needs	
Structure of Committee / Chairperson	Linda Hamman	The group discussed chairperson status for the committee and how chairpersons lead the group in accomplishing the Committee goal of the Youth Conference. The group chose George Garcia as Chairman and Jay Dashefsky as Co-Chairman.	*The members chose Mr. George Garcia as Chairman of the Committee and Jay Dashefsky as Co-Chairman of the Committee.

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		If any of the young adults know of anyone who would like to serve on this committee, please contact Jill Wendt at wendtj@azdhs.gov (602-364-3356) or Beverly Plonski-Fuqua at plonskb@azdhs.gov (602-364-3291).	*Invite other youth to participate in committee. Contact Jill Wendt (wendtj@azdhs.gov 602-364-3356) or Beverly Plonski-Fuqua (plonskb@azdhs.gov 602-364-3291) to add members.
Structure of Committee /Who else should be invited to this committee	Debbie Gilmer, Western Maine Partnership, UMF Theresa Armstrong	Advised the committee that she had heard that there is a young adult group that is involved in legislation in Arizona and this group may be worth inviting into the committee. Ms. Armstrong asked if we were considering inviting participants from the Arizona Governor's Office. The Governor's Office for Children, Families and Youth (CFY) could be a good source for members.	*Potential invites to the ISG Young Adult Transition Committee include: -Young Adults involved in AZ legislation (<u>Governor's Executive Order 2004-14</u>) -Theresa to contact AZ Governor's Office of Children, Youth and Families for possible invites.
Structure of Committee/ Website development	Linda Hamman	Informed the group that the work that is done by the Committee will be on the www.azis.gov website.	*Visit www.azis.gov for all current ISG Young Adult Transition and IS Grant information.
Review / Approve Young Adult Transition May 2006 Status Report to Task Force	Linda Hamman	Advised the committee that the ISG Young Adult Transition Committee's May 2006 Status Report went to the ISG Executive Task Force on May 24, 2006. Ms. Hamman read through the ISG Young Adult Transition Committee's May 2006 Status Report to the ISG Task Force.	*ISG Young Adult Transition May 2006 Status Report to the ISG Task Force is on www.azis.gov website for review
	Jason Geroux, AZ Governor's Council on Developmental Disabilities	I have a question regarding identifying additional members. Are you looking for groups that have direct access to family and youth or are you looking for technical assistance and expertise in the goals?	

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	Linda Hamman	Both would be good.	
	Jason Geroux	If you are looking for more front line families and youth, there is another organization that may be able to do that for you. It is Arizona Autism Support at 480 241 8876.	*Additions to the May 2006 Young Adult Transition Status Report include: -Insertion of Debbie Gilmer on line item reference to the National Center on Healthy and Ready to Work -Add Arizona Autism Support at 480 241 8876 to identifying additional members listing.
Review / Approve Young Adult Transition May 2006 Status Report to Task Force (con't)	Mattie Cummins, Brain Injury Association of Arizona	Try to coordinate with the Governor's Council on Spinal and Head Injuries.	*Invite members to the committee from the Governor's Council on Spinal and Head Injuries. (Chrystal Snyder, Executive Director - csnyder@azdes.gov)
	Linda Hamman	Did any of you have any recommendations that you had talked about and possibly were missed on the report? The next ISG Task Force Meeting is in August. We can re-visit this report, if any one thinks of anything.	*Next ISG Task Force Meeting is 8-23-06 1pm-3pm Room 345A-ADHS Bldg.
Review GAPS Questionnaires	Linda Hamman	<p>One of the tasks that each of the ISG Committees has is to be able to review the things that any other committee is doing. We have for your review, the GAPS Questionnaires (Guidance to Adolescent Preventive Services).</p> <p>The Care Coordination Study (aka Medical Home Project) is a project outlined in the Integrated Services Grant. The ISG Quality Improvement Clinical Committee chose some basic screening tools to use in that Medical Home Project and recommended them to the Task Force in May 2006. The tools QI Clinical recommended are varying in targeted age groups and address ages up to 18 (different recommended tools for different age groups). The Adolescent Health Committee took a look at those tools and recommended the GAPS Questionnaires for review by the QI Clinical</p>	*One ISG grant objective that will encompass all ISG Committees is the Care Coordination Study <aka Medical Home Project>

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		Committee and other committees because GAPS is specific to adolescents and parents. That is how it got to us for comments.	
Review GAPS Questionnaires (con't)	Linda Hamman	<p>Within this project, 2 to 4 primary care and/or pediatric practices will be chosen whereby a care coordinator and a screener will be placed within those practices. We will study, if a care coordinator is involved with the clinical process; and if there are screenings done, what better outcomes for children and youth would occur by using that enhanced process?</p> <p>So they are looking at specific screening tools that would help identify further issues that <i>may</i> be occurring with children and youth. Right now, the standard tool that is used is the EPSDT, Early Periodic Screening and Diagnostic Tool. It's a basic tool from AHCCCS. However, things may get missed with such a basic tool.</p> <p>One of the tools that QI Clinical recommended was a screening tool for autism. That is the M-CHAT, ages 18 month to 4 years. Also, the PEDS (Parents' Evaluation of Developmental Status) tool (birth-8yrs). The GAPS Questionnaires has been recommended for review because the 6 tools QI Clinical has already recommended to the Task Force go up to age 18. So we are charged with reviewing this specific tool (GAPS) that looks directly at young adults in the 18 and after age group.</p>	
	Group	The ISG Young Adult Transition Committee members reviewed the GAPS Questionnaire tool and provided feedback and observations. Please see attached documentation "ISG Young Adult Transition Committee Feedback on GAPS".	*See attached documentation "ISG Young Adult Transition Committee Feedback on GAPS" for all feedback and observations made by the group.
	Linda Hamman	This feedback will definitely help determine how we can better support the positions of the care coordinators and screeners in the Medical Home Project. We need to ask the questions you did. As in, "If we are going to do this, what tool will be used, and who will get the tool (age groups, etc)". Additionally, many physicians have trouble with making referrals in cases of children with special health care needs. Maybe the care coordinator can help the physician in these areas too.	

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		As the Medical Home Project is streamlined, these questions are important. There have been positive results reported from other states doing these medical home projects so we are hoping that the project will have positive results too. All ISG Committees will be kept informed on the progress.	
AZ DOE-2006 Transition Conference “Voices, Choices, and Results – Youth in the Spotlight”	Theresa Armstrong, AZDOE	<p>Handed out the AZDOE Arizona Transition Leadership Team information, a Conference Overview of the “2006 Transition Conference “Voices, Choices, and Results – Youth in the Spotlight”, and the registration information for the conference.</p> <p>A specific session at the conference will concentrate on youth empowerment. We have Leslie Coull from Canada coming in for those sessions. We are trying to invite more youth to the conference so it is good that this Committee is involved.</p> <p>The Arizona Transition Leadership Team (ATLT) is many agencies coming together 2 times a year. The Board of this team is currently re-writing the Mission Statement and Guiding Principles. They are not changing any dynamics, just cleaning up some language. We will keep you updated on that.</p>	<p>*Supplied information on -AZDOE Arizona Transition Leadership Team information -AZDOE Conference Overview and registration information on the 2006 Transition Conference “Voices, Choices, and Results – Youth in the Spotlight” – September 18th & 19th. -go to www.ade.az.gov and click on “Calendar of Events”- then select September 2006 and click on the date of 18. -contact Jeannette Zemeida at 602-542-3855 if there is any difficulty.</p>
	Theresa Armstrong	<p>As you read the Transition Leadership Team information, you can see the partnering agencies and entities, the Mission Statement, and what topics this team is currently focusing on. AZDOE is getting together with OCSHCN for planning and streamlining the youth scholarships aspect of the conference. We are waiting on and trying to gather information on what funding is available and how many scholarships there would be.</p> <p>The Conference Review (part of handout) is information on the September 18 & 19th conference – Voices, Choices, and Results – Youth in the Spotlight. I encourage all youth to attend and to share this information with others. It has all the information on the registration.</p>	*Youth scholarship planning is currently being undertaken. Waiting on information on funding to determine how many scholarships can be offered.

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Brainstorming and review about ISG Young Adult Summit / Conference	Group discussion	<p>The members of the committee gave ideas on the content, topics of interest, and planning steps of the ISG Young Adult Transition Summit / Conference.</p> <p>Please see the following:</p> <ul style="list-style-type: none"> *Tentative date is set for April 21, 2007 *Have a fun event in the evening planned *Site must be ADA-friendly *How many attendants are expected? (150-200) *Scholarships available and coordinated (Theresa) *What kind of sponsorships will there be? *Location - Phoenix Airport Marriott, Doubletree Suites on 44th Street *Overnight stays – get specifics because some people will have to stay overnight if conference has early activities or late activities, etc. -Accessibility to unisex bathrooms (some young adults have mom or dad helping with bathrooms-female that help males and males that help the females need this) 	<p>*See text in DISCUSSION section.</p> <p>*Location – Ms. Cummins will forward Airport Marriott information to Linda Hamman</p> <p>*Send listing to Committee members to review for next meeting.</p>
	Jason Geroux,	<p>Jason invited all the ISG Young Adult Transition Committee members to be a part of the Governor’s Council on Developmental Disabilities. Please contact Jason Geroux, Public Outreach Coordinator / District Liaison Arizona Governor’s Council on Developmental Disabilities Post Office Box 2845 Apache Junction, Arizona 85217-2845 Jason@azgcdd.org AND Jason@arizonaautismsupport.org Phone: 480-983-2977 Mobile: 520-820-2589 Toll Free: 1-866-701-5575 Fax: 520-423-3400</p> <p style="text-align: center;">OR</p> <p>Jami Snyder, Executive Director, Arizona Governor’s Council on Developmental Disabilities 3839 North Third Street, Suite 306 Phoenix, Arizona 85012 jsnyder@azdes.gov Phone: 602-277-4986 Fax: 602-277-4454</p>	<p>*Open invite to ISG Young Adults to be a part of the Governor’s Council on Developmental Disabilities. -Contact Jason Geroux</p>
Next Meeting		August 24, 2006, 1pm-3pm, ADHS Bldg., Room 345A	<p>*Send “Topics for Conference” (with planning next steps included) document to all ISG Young Adult Committee members</p>

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			to add resources and ideas to for next meeting.

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ISG Young Adult Transition Committee
Feedback on GAPS Questionnaires
7-20-06

- How will it be administered? More of the ABC's of how it is going to use.
- How will it be administered for people without ability to read or write? Literacy level and ability to complete it themselves must be addressed, if used.
- If read to them, they have to have the ability to opt out of questions
- Need education of physicians and awareness of physicians to issues that a person with physical disabilities might encounter.
- Patient should have a choice *not* to answer the questionnaires.
- Patient should have the choice to stop using the tool after it has been started, if so desired.
- Has to be totally up to patient –if they want to engage in the questions
- Too personal
- Will it be answered?
- These tools can be invasive. There are case managers that do *home visits* and that is not as invasive.
- Where will it go and where does the information go?
- Answers may not be honest.
- Answers may not be positive but nothing may be wrong – what is considered normal first
- Research must be done on the guidelines for administering.
- What is the purpose? Is it for a referral?
- Who does the physician tell about the referral? The adolescent? Or do they have to tell the parent about a referral? Could get very uncomfortable for the youth.
- Youth may answer the questions but youth may not want the doctor to talk to them about their answers. Have to inform and ask patient what the questionnaire intends to do and what it means to answer it.
- Is it comfortable for the patient? Not meant to make feel uncomfortable.
- People with physical disabilities can't always travel alone or go to a doctor alone. Parents come with you. But some youth don't/won't want to answer these with your parents in attendance (even if they are just in another room)
- Do it online somehow. Prior to appointment or having computer and/or PDA in waiting room. Research the doctors that are using online services in waiting rooms. What tools are in place already?
- Some doctors who serve adolescents already have screening tools (some online) and have a process in place (notify you of how many hours you must come in previous to the appointment and complete it, etc). They may have a process of how they treat sensitive issues. Find out what current process(es) are being used by the doctors in regards to adolescent screening tools or questionnaires. Compare and see if valid to use.
- Research the doctors that are already using the tools.
- If the information is online, the person can get their own information and give, maybe, better information. The young adult knowing that the doctor will get the information this way, may help them answer more questions and be more honest. But the reading and literacy level of being able to do it online is a concern.
- When people go to the doctor, the nurse asks questions first as they go into the room. Can she ask about the tool then? Do they want to do it?

- Nurses should be already asking youth questions “is there anything specific you would like to talk to the doctor about?” (when the youth is being directed to a room or checking in at the desk). They can ask questions.
- Are the youth comfortable with the parents knowing? Each patient will be different so different approaches are necessary.
- Is GAPS being administered because something is already “wrong”? Must be clarified.
- The screener is in the clinical setting administering these tools, they must be aware of this and trained, which is “if someone says to you, “no I am uncomfortable”; then it should be the end of the use of the tool.
- Must have high level health training of the screener and care coordinator (qualifications).
- Positive type questionnaire but gives possible impression that physician/screener is searching for negativity.
- Is age defined within the GAPS tool? Define the ages.
- Middle-Older Questionnaire font should be increased– format issue.
- Format leads to questions of maintaining confidentiality (Middle-Older Questionnaire).
- Trained person administering must have high comfort level with individual. A relationship established.
- Must ask if individual is comfortable answering the questions themselves or having someone else asking the questions.
- Could it be verbal instead of written?
- Don’t exclude if individual cannot read well, write well or talk well or even hear. How would be it administered in specific situations like this?
- Must have time to administer
- Doctors don’t have time to read all this and make a referral
- Must include everyone and make it accessible to all.
- Can these questions be asked without parental consent?
- Young adults may be a bit “scared” that information will get back to parent. Just by the parent going to the visit with the doctor.
- Hot topics may not get answered (sexual activity, alcohol, cigarettes).
- Is the physician giving any type of information BACK to the patient? What will the referral be?
- It does touch on subjects that need to be asked to adolescents. The doctors have kids going in and out and may not be hitting these subjects and the opportunity to intervene is lost. In questionnaire form, I do not know how effective it will be.
- When we think about an adolescent coming into doctor’s office, probably for the first time for his screening, the questionnaires are given, and the adolescent doesn’t know the doctor....I wouldn’t answer it.
- These questions need to be asked. But this tool might not be the best avenue to do the asking. Maybe it should be verbal. Not use a form at all? Do you have to use the whole form? What about just asking some of the questions during the visit?
- Perhaps a tool that is a bit more brief.
- Must have a long term relationship with patient. Sometimes, when you go to the doctor at a clinic, etc. you see an intern resident that is only there for about 3 months or so. You need someone on a personal level that will coordinate future care.
- How about another adolescent asking the questions to the adolescent.
- Brochure development may help on some topics – for adolescents and for the doctors